

# **BURDEN AND COPING STRATEGIES AMONG FAMILY CARE GIVERS OF CHILDREN WITH AUTISM**

*Thesis*

*Submitted For Partial Fulfillment of the Requirement  
of Master Science in Nursing (Psychiatric Nursing)*

*By*

**Manal Ahmed Salama**

*B.Sc.N. Cairo University  
Supervisor of Mental Health Psychiatric Nursing  
Department  
Technical Health Institute - Embaba  
Ministry of Health*

Faculty of Nursing  
Ain Shams University  
2009

# **BURDEN AND COPING STRATEGIES AMONG FAMILY CARE GIVERS OF CHILDREN WITH AUTISM**

*Thesis*

*Submitted For Partial Fulfillment of the Requirement  
of Master Science in Nursing (Psychiatric Nursing)*

*Supervisors*

**Prof. Dr. Zeinab Lotfi**

*Professor of Psychiatric Mental Health Nursing  
Faculty of Nursing - Ain Shams University*

**Dr. Mona Hassan**

*Lecturer of Psychiatric Mental Health Nursing  
Faculty of Nursing-Ain Shams University*

**Dr. Nahla El-Sayed Nagy**

*Assistant Professor of Psychiatry  
Faculty of Medicine - Ain Shams University*

Faculty of Nursing  
Ain Shams University

2009

*Abstract***Burden and Coping Strategies among Family Care Givers of Children with Autism**

By

***Manal Ahmed Salama Mohamed***

Autism refers to a condition of being dominated by subjective self centered trends of thought or behavior which are not subject to correction by external information, disharmony of development where in children despite excellent motor skills. They fail to mature socially, so the family care givers of those children suffer from different degrees and types of burden which lead to use some strategies of coping. This study aimed at exploring the burden facing main family care givers of children with autism and their coping strategies as perceived by them. The sample consisted of 92 mothers and (8) others, family care givers. That 4 of them were grandmothers and the other 4 were grandfathers that accompany their autistic children during regular follow up. The study was carried out in (1) Institute of Childhood Studies, Ain Shams University, and (2) Abbasia Out patient Child Clinic, Ministry of Health. Tools used for data collection included: 1) Pre-designed questioner to assess socio demographic data of the children with autism and their main family care givers, 2) Burden Interview Questionnaire, to assess the extent to which care givers perceive their emotional and physical health social and financial status, 3) Coping Inventory Scale to assess care givers strategies for coping with stress associated with raising a child with autism. Result revealed that there are positive correlations between emotional social burden that care givers suffer from and their children's degree of illness, age and sex. On the other hand, there is a highly significant relation between care givers' negative coping strategy and their age. The study concluded that family care givers of children with autism are suffering from emotional and social burden. The study recommended the importance of developing social awareness through the media means about the autistic disorders which the child with autism can get the full benefits of proper methods in dealing with and preparation of workshops for medical and nursing students and social workers to develop their awareness and increase their knowledge and practice on how to deal with the child with autism.

---

**Keywords:** Autism. Emotional, social burden. Coping strategies. Family care givers.

## INTRODUCTION

Autism is defined as a condition of being dominated by subjective self centered trends of thought or behavior which are not subject to correction by external information, preoccupation with inner thoughts, daydreams, fantasies, egocentric, lacking objectivity and connection with reality (*Miller et al., 2002*). However, *Buton and Howard (2007)* defined autism as a brain disorder that typically affects a person's ability to communicate, form relationships with others and respond appropriately to the environment.

Today it is estimated that one in every 150 children are diagnosed with autism and 3 to 4 times more common in boys than girls, and one over ten of millions worldwide are affected by autism (*Richard & Robert, 2002*). The prevalence rate in Egypt is 152,234 people (*African National Information of Mental Health, 2008*).

Childhood is a demanding and challenging period for all parents, and when a child has a problem, the demands and challenges are magnified. When the problem is autism, one of the most devastating and least understood mental disorders of childhood, it is hard to imagine how parents and siblings cope (*Stokstad, 2001*). Parents are usually the first to notice unusual behaviors in their child and have to focus on their autistic child while making sure they do not neglect other relationships (*Regional Public Forums, 2002*).

An autistic child in the family creates a situation that requires understanding and support from extended family, friends, the community, and professional caregivers. Unfortunately, most families with an autistic child know little about autism as a disease, or its implications (*Holmes & Carr, 2005*).

The experience and the reality of an autistic family's world, should be understood by the newly diagnosed, or inexperienced autistic child's family now embarking on an atypical life-long journey (*Berkow, 2002*). These parents are generally left in shock and disbelief, not knowing what course of action to take to help their autistic child and their families, including the sibling of the autistic child survive this devastating disease (*Stokstad, 2001*). They must learn how to cope with stressful situations and accept a life long transformation learning process to continually adapt to changing circumstances. The experience should be understood by extended family, friends and the community. If all could understand the experience of the autistic family, they could empathize, not sympathize, be supportive not avoidant, be accepting, not rejective (*Koegel, 2002*).

The family of a person with an acute or chronic illness is subjected to a variety of stressors, including, changes in family structure and roles, isolation from the loved person, loss of control over normal routines, feelings of helplessness, guilt, or anger, lack of information about care, concern for future

economic stability (*Phipps, 2002*). Parents are encouraged to express their feeling as this helps release some of the tension that builds up, and helps in the way to more move forward (*Koegel, 2002*). Coping strategies are behaviors that family members use to resolve conflicts, eliminate stressors, acquire and develop social skills (*McDonald et al., 1999*).

The major role of the medical professionals and nurses is to orient and instruct the newly diagnosed or inexperienced autistic child's family about the particular disorder and its lifelong follow up as well its complications (*Koegel, 2002*). Additionally, professional nurses can play an active role in children's medical follow up by providing support and resources that enable autistic family adaptation to the crisis as well as developing a positive attitude toward particular disorder (*Holmes, 2005*).

Meanwhile, the nursing staff in the child's outpatient clinic can play an important role through exchanging information and experiences among care givers to fit their needs and to support each other (*Mohor, 2006*).

## **AIM OF THE WORK**

The aim of this study is to explore the burden facing main family caregivers of children with autism and their coping strategies as perceived by them.

## **Definitions of autism**

The term autism refers to preoccupation with inner thoughts, daydreams, fantasies, egocentric and subjective thinking (*Miller & Kean, 2002*). Meanwhile, the disorder is characterized by a remarkable disharmony of development where in children, despite their excellent motor skills and retentive memory, they fail to mature socially, i.e. to form any emotional bonds with parents and other individuals, and often to learn to speak. It is the discrepancy between their excellent motor skills on the one hand and the global sociality, lack of or restricted communicative speech (*Adams, 2005*).

Other researchers identified autism as a neurodevelopment disorder characterized by impaired social interaction and communication, repetitive and stereotyped patterns of behavior, and uneven intellectual development often with mental retardation (*Albert & Spaine, 2006*).

Furthermore, Leokanner a former child psychologist at Johns Hopkins University, first introduced autism to medical literature in 1943. Kanner chose the word (autistic) because the children had in common an extreme aloneness from the beginning of life and an anxious, obsessive desire for the preservation of sameness (*Nadig, 2007*).

However, some researchers identified autism as a brain disorder that typically affects a person's ability to communicate, form relationships with others and respond



appropriately to the environment (*Buton & Howard, 2007*). It has been accepted by some researchers that the pervasive development disorder, also known as autism spectrum disorders (ASDs) is a cognitive impairment characterized by deficiencies in communication, social interaction, and creative or imaginative play. This spectrum includes autistic disorder (autism), Asperger's Syndrome, pervasive development disorder not otherwise specified, and Rett's Syndrome. Individuals on this spectrum often exhibit stereotypical, self-stimulatory behavior such as rocking, hand flapping or vocalization (*Limperopoulos, 2008*).

### **Epidemiological studies:**

Epidemiological surveys conducted between 1966 and 1998 declared that the most robust estimates that could be made from available data were that approximately 18 people per 10,000 were diagnosed with the spectrum (autistic disorder, Asperger's disorders, pervasive disorder) and 5 people per 10,000 were diagnosed with the discrete diagnostic category of autistic disorder and a male - female ratio of 3.8 to 1 existed (*Andrew & Cashin, 2005*).

Meanwhile, throughout the 1980s and early 1990, researchers had associated autism with mental retardation in 80% of cases, however during the past decade the autism diagnosis has broadened as it was recognized that the same triad of impairment existed in a wider population of individuals (*Fombonne & Andrew, 2001*).

---

Today, it is estimated that one in every 150 children is diagnosed with autism. An estimated 1.5 million individuals in the U.S. and one over ten of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently (*Robinson et al., 2008*).

**Etiology:**

There are different levels of severity and combinations of symptoms in autism. There are probably multiple causes. The best scientific evidence available to us today points toward a potential for various combinations of factors causing autism (*Robinson et al., 2008*).

Little is known about what causes autism, but some theories exist. Autism research reports that it is the result of a dysregulated immune system in children that is triggered by a virus or genetic disposition or may be caused by intrauterine, prenatal or neonatal stress or trauma (*National Institute of Mental Health, 2002*).

It is generally accepted that autism is caused by abnormalities in the brain structure or functions, however scientists now know that a number of problems may interfere with normal brain development, cells may migrate to the wrong place in the brain or due to problems with the neural pathways

or the neurotransmitters some parts of the communication network may fail to perform. A problem with the communication network may interfere with overall task coordinating sensory information, thoughts, feelings and actions (*Herbert & Sharp, 2000*).

Furthermore, some of national information of mental health researchers are investigating genetic causes. The role that heredity and genes play in passing the disorder from one generation to the next, others are looking at medical problems related to pregnancy and other factors (*National Institute of Mental Health, 2002*).

Several studies of twins suggest that autism or at least a higher likelihood of some brain dysfunction can be inherited, for example identical twins are far more likely than fraternal twins. However autism does not appear to be due to one particular gene (*Morton & Frith, 1995*).

Pregnancy and other problems throughout pregnancy, the fetal brain growing larger, and more complex, as new cells in specialized regions and communication network form. During this time anything that disrupts normal brain development may have lifelong effects on the child's sensory language social and mental functioning (*London & Elzel, 2000*).

For this reason, researchers are exploring whether certain conditions like the mother's health during delivery or other environmental factors may interfere with normal brain

development. Viral infection like rubella (German measles) particularly the first three months of pregnancy may lead to variety of problems possibly including autism and retardation (*Zysk & Eleen, 2004*).

In addition to that, genetic factors in several surveys between two and four percent of siblings of autistic persons have been found to be afflicted with autistic disorder, a rate of fifty times greater than in general population (*Harold & Kaplan, 1994*).

As regards immunological factors, some evidence suggests that immunological incompatibility between the mother and the embryo or fetus may contribute to autistic disorder. The lymphocytes of some autistic children react with maternal antibodies raising the possibility that embryonic neural or extra embryonic tissues may be damaged during gestation (*Buton & Howard, 2007*).

Some studies hypothesize that environmental toxins or immunizations and being phased out nationally due to safety concerns, are behind the increase in prevalence. Other studies have not confirmed a link to immunizations (*Johnson, 1999*). Still others believe that a combination of factors may be responsible (*Prober, 1999*). Several federally funded studies are investigating a variety of causes including environmental toxins, immunization and genetics (*National Institute of Mental Health, 2002*).

## Associated features

**Table (1):** Difference in the Behaviors of Infants with and without Autism

<b>Infants with Autism</b>	<b>Normal Infants</b>
<b>Communication</b>	
<ul style="list-style-type: none"> <li>• Avoid eye contact</li> <li>• Seem deaf</li> <li>• Start developing language, then abruptly stop talking altogether</li> </ul>	<ul style="list-style-type: none"> <li>• Study mother's face</li> <li>• Easily stimulated by sounds</li> <li>• Keep adding to vocabulary and expanding grammatical usage</li> </ul>
<b>Social relationships</b>	
<ul style="list-style-type: none"> <li>• Act as if unaware of the coming and going of others</li> <li>• Physically attack and injure others without provocation</li> <li>• Inaccessible, as if in a shell</li> </ul>	<ul style="list-style-type: none"> <li>• Cry when mother leaves the room and are anxious with strangers</li> <li>• Get upset when hungry or frustrated</li> <li>• Recognize familiar faces and smile</li> </ul>
<b>Exploration of environment</b>	
<ul style="list-style-type: none"> <li>• Remain fixated on a single item or activity</li> <li>• Practice strange actions like rocking or hand-flapping</li> <li>• Sniff or lick toys</li> <li>• Show no sensitivity to burns or bruises, and engage in self-mutilation, such as eye gouging</li> <li>• Seek pleasure and avoid pain</li> </ul>	

*Adopted from: Growth and Development, Milestones (1995) and Abrams et al.,(2004)*

### ***Social symptoms***

From the start, most infants are social beings. Early in life, they gaze at people, turn toward voices, endearingly grasp a finger, and even smile. In contrast, most children with autism seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem to prefer being alone. They may resist attention and affection or passively accept hugs and cuddling (*Volkmar, 1999*).

Later, they seldom seek comfort or respond to anger or affection. Unlike other children, they rarely become upset when the parent leaves or show pleasure when the parent returns. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of response (*Growth and Development, Milestones, 1995*).

### ***Diagnosis of Autism:***

Parents are usually the first to notice unusual behaviors in their child. In many cases, their baby seemed "different" from birth-being unresponsive to people and toys, or focusing intently on one item for long periods of time. The first signs of autism may also appear in children who had been developing normally. When an affectionate, babbling toddler suddenly becomes silent, withdrawn, violent, or self-abusive.

Even so, years may go by before the family seeks a diagnosis. Well-meaning friends and relatives sometimes help parents ignore the problems with reassurances that "Every child

is different. Unfortunately, this only delays getting appropriate assessment and treatment for the child (*Mohor, 2006*).

**Table (2):** Indicators of Normal Development

Age	Skills or Abilities Awareness and Thinking	Communication	Movement	Social	Self-help
<b>Birth-3 months</b>	Responds to new sounds. Follows movement of hands with eyes Looks at objects and people	Coos and makes sounds. Smiles at mother's voice.	Waves hands and feet. Grasps objects Watches movement of own hands.	Enjoys being tickled and held Makes brief eye contact during feeding	Opens mouth to bottle or breast and sucks
<b>3-6 months</b>	Recognizes mother Reaches for things	Turns head to sounds and voices Begins babbling Imitates sounds Varies cry	Lifts head and chest Bangs objects in play	Notices strangers and new places Expresses pleasure or displeasure Likes physical play	Eats baby food from spoon Reaches for and holds bottle
<b>6-9 months</b>	Imitates simple gestures Responds to name	Makes nonsense syllables like gaga Uses voice to get attention	Crawls Stands by holding on to things Claps hands Moves objects from one hand to the other	Plays peek-a-boo Enjoys other children Understands social signals like smiles or harsh tones	Chews Drink from a cup with help
<b>9-12 months</b>	Plays simple games Moves to reach desired objects Looks at pictures in books	Waves bye-bye Stops when told "no" Imitates new words	Walks holding on to furniture Deliberately lets go of an object Makes marks with a pencil or crayon	Laughs aloud during play Shows preference for one toy over another Responds to adult's change in mood	Feeds self with fingers Drinks from cup
<b>12-18 months</b>	Imitates	Shakes head to mean	Creeps upstairs	Repeats a	Moves to